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Article (Accepted Version)

Lowton, Karen and Gabe, Jonathan (2003) Life on a slippery slope: perceptions of health in adults with cystic fibrosis. *Sociology of Health and Illness*, 25 (4). pp. 289-319. ISSN 0141-9889

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Life on a Slippery Slope: Perceptions of Health in Adults with Cystic Fibrosis

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Word count: 11 665 (main text)

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Abstract

This paper focuses on how adults with cystic fibrosis (CF) attending a specialist CF centre in the UK perceive their health. In common with many other genetic diseases, CF is traditionally conceptualised as a fatal childhood disease, yet the average survival age for those with CF has been steadily rising over the past half century. Thus it is now predicted that those born in 1990 will live on average for 40 years. To date, however, most sociological work has focused on children or adolescents affected by CF rather than on adults between the ages of 18 and 40, the focus of the study reported here. The paper shows that these adults' varying perceptions of health are related to the effects of CF, its treatment, and the context in which adults are placed. Four concepts of health are identified (health as 'normal', controllable, distressing and a release) along with certain styles, ways of coping and related strategies. Through these analytic distinctions the paper aims to make a contribution to the sociological understanding of lay concepts of health in adults with childhood or genetic disease.

Keywords: health perceptions, cystic fibrosis, adults, styles, coping, and strategies

Introduction

Cystic Fibrosis (CF) is the most common autosomal recessive genetic disease in the United Kingdom today, with an estimated annual incidence of 1:2415 births (Dodge et al. 1997). Adults with CF in the UK are a growing group, increasing by about 150 adults per year (Dodge et al. 1997). In the early 1930s, 70 per cent of people with CF died before their first birthday (Anderson 1938). The median survival age in the UK in 1994 was 31 years (Dodge et al. 1997), with children born in 1990 being predicted to live for 40 years on average (Elborn et al. 1991). However, the variability and unpredictability of the disease course means that there is no particular age at which mortality rises sharply (Dodge et al. 1997).

The major symptoms of CF arise from abnormal sticky secretions in the respiratory and digestive tracts, produced by the 'CF gene' identified by scientists in 1989 (Rommens et al. 1989). The most common symptom of CF is recurring chest infections resulting in lung damage; the majority of deaths occurring through respiratory failure (Madden 2000). Other associated problems thought by doctors to arise from these sticky secretions include an inability to absorb fats and protein, leading to weight loss, CF-related diabetes (Dodge and Morrison 1992) and infertility, especially in males (Sawyer 1996). Furthermore, other medical problems may become apparent earlier in the adult's life compared to people without CF, for example chronic pain (Ravilly et al. 1996), osteoporosis (Aris et al. 1996) and some types of cancer (Sheldon et al. 1993).

Current routine treatment for CF is palliative rather than curative and so aims to maintain health by treating the symptoms of the disease as they occur. The mainstays of daily therapies to treat these symptoms over the past three decades have been chest physiotherapy, pancreatic enzymes and regular courses of antibiotics. Most treatment is carried out in the adults' homes

with acute episodes of illness requiring hospital admission. As health fails, organ transplantation, most commonly heart-lung transplantation, may be offered. However, the shortage of suitable donor organs in the UK means that around half of adults with CF on the transplant list will die before donor organs are found (Ryan and Stableforth 1996, Hodson 1998). Following the identification of the 'CF gene', the medical focus of potential new treatment is on gene replacement therapy (GRT). However, this is still experimental; although much research is undertaken with adults attending specialist centres this current group are unlikely to receive GRT as a licensed treatment.

Medical sociologists have written much about chronic illness and the disrupted biographies of adults who have generally enjoyed a long span of good health before 'suffering the onset of symptoms' (Bury 1982). Some attention has also been given to chronic disease diagnosed in childhood with the focus being firmly on the child (in the context of CF see, for example, Bluebond-Langner 1991 and Venters 1981). Rarely, however, do researchers return to investigate the case of adults living with a disease widely regarded as one of childhood, with the notable exception of Thomas (1998), in the case of adults with polio. Not surprisingly, therefore, very little has been written about the experiences of adults with CF even though this represents a rich area for inquiry.

One particular issue that faces adults who have been ill since childhood is how they understand their condition. Do they perceive themselves to be healthy or do they see themselves as ill? These questions have been explored in three distinct ways in the literature on lay perceptions of health and illness. The first considers what healthy people perceive 'health' to be. For example, Blaxter (1990) used survey methods to explore definitions of health amongst British respondents and identified nine concepts of health from their

statements. These included health as functional capacity and health despite disease. Similarly, d'Houtard and Field (1984) surveyed French respondents to define the meaning of health and amassed 41 themes that were classified into 10 categories. These included health as equilibrium, hygiene and absence of sickness. Around the same time, Crawford (1984) conceptualised health as 'self-control' and 'release', from interviews with healthy Americans; while more recently Saltonstall (1993) reported that 'healthy' people in the United States closely associated health with the more general notion of 'well being' and positive aspects of 'being in the world'.

The second type of investigation has focused on how those with a chronic physical illness live with their condition rather than exploring perceptions of health. Examples of this genre include Charmaz's (1983) study of the 'loss of self' of the chronically ill in which issues such as social isolation, discreditation and the restriction of daily life were examined. Similarly, Locker's exploration of the disadvantages caused by chronic illness focused on practical daily activities that, through illness, become 'problems that need to be solved' (1983: 6). In an insightful paper Bury (1991) distinguishes three modes of adapting to chronic illness; coping, style and strategy. According to Bury coping refers to the cognitive processes people use to help tolerate and 'put up' with illness, while style focuses our attention on 'the way people respond to and present important features of their illness or treatment regimens' (1991: 462, *author's italics*). Strategies on the other hand refer to what people do in the face of chronic illness and the resources they use to maximise a favourable outcome. According to Bury, the latter actions 'may bring about a greater degree of consciousness and calculation in everyday life than is normally experienced' (1991: 462). In these approaches the focus is on managing chronic illness and treatment, rather than explicitly examining the concepts of health amongst people with chronic disease.

The third approach to the sociological study of health and illness concerns the perceived causes of health and illness for healthy people. Blaxter (1983) interviewed middle-aged, Scottish women from poor social backgrounds and found that the categories used to describe causes of illness were infection, heredity, family susceptibility and environmental agents. In an interview study of perceptions of both health and illness amongst French people from the middle and 'intellectual' classes, Herzlich (1973) noted that her respondents believed that health came from within an individual (i.e. internal) whereas the cause of illness was external, for example, germs, or a particular way of life. Similarly, Pill and Stott (1982, 1985) found that at least half the sample of wives of skilled manual workers in South Wales held fatalistic views about health and illness, whilst the remainder believed that individual behaviour played some part. The concept of health as being an attitude of mind, which can additionally control physical health, has also been noted previously in the sociological literature (Calnan 1987).

The current study brings these three approaches together by examining what health means to people who have been diagnosed as chronically ill since early infancy. Despite having CF, the adults in this study predominantly spoke of themselves as being healthy, either currently or in the recent past.

Methods and Sample Characteristics

The 31 adults involved in this study all attended a regional specialist centre for the care and treatment of CF and ranged in age from 18 to 40 years. A list of adult patients living in southeast England was prepared from the specialist centre's CF department database, amounting to around 40 per cent of the total number of adults attending the department (Yung et al. 1999). A meeting was held between the first author and CF department staff to agree the eligibility criteria. It was decided to exclude those who were judged by the staff to be in

extremely poor health and those who had great difficulty in communicating in English because it was not their first language. Two patients were excluded on these grounds. A further 14 patients were excluded because they were a sibling of a patient who had already been approached to participate in the study. This decision was taken to avoid any undue pressure on the second sibling to participate in the study, especially if their brother/sister had refused to take part.

After the staff had checked to make sure that those in the sample had not died very recently, they were written to by the first author inviting them to participate in the study. Patients also received a letter of introduction from the CF consultant and CF Nurse Consultant. Overall, 26 per cent (47/183) of those approached agreed to take part, after follow-up and reminder letters. This acceptance rate was much lower than anticipated and may have been to do with the subject matter of the research; patients might have responded more positively to research involving new therapies than to a sociological study. For instance, a previous sociological research project exploring screening for Downs' syndrome, thalassaemia and CF amongst people with these diseases reported a similar response rate of 25 per cent amongst adults with CF (Alderson, personal communication).

Thirty-one respondents were subsequently interviewed in their own homes for between 1–1.5 hours on average during 1997/8, with the aid of a topic guide. Reasons for respondents not being interviewed were subsequent refusal, living out of the study area, hospitalisation and death. Besides exploring respondents' perceptions of their health, attention was also focused on issues such as living with the disease and disclosing their condition to others, the risks and benefits of their current and future potential treatments and their hospital care. Lung function, height and weight were measured as part of a larger study. A Vitalograph lung spirometer was

used to record participant's forced expiratory volume in one second (FEV1). This value was then expressed as a percentage of that predicted for a 'healthy' person of the same age and height (FEV1% predicted). Confidentiality was assured for all participants by informing them that what they said would not be shared with either the hospital or their relatives. Patients were told that all interview material would be made anonymous by using pseudonyms in any reports. Consent forms were signed by respondents to comply with the requirements of hospital research.

Interviews were tape-recorded and fully transcribed. Coding was undertaken using the ATLAS-ti software programme for qualitative data. Codes were attached to a segment of text such as a word, phrase, sentence or paragraph. These codes were then grouped into categories, providing the conceptual foundations for analysis as described by Dey (1993). Development of the majority of conceptual categories had started during the course of interviews and were subsequently developed analytically with conceptual relations being established (Strauss 1987).

Patients were interviewed in order to provide information about the diversity of experience of living with CF and being treated in a specialist clinic for the disease. Although there was a high non-participation rate, the findings are likely to reflect the views of other adults with CF in the UK, as between 53–93 per cent of all people with CF in this country are estimated to attend some type of specialist CF clinic (CSAG 1993). More importantly, given that the sample was theoretical, in that interviewees verified emerging theory as more interviews were conducted (Strauss 1987), and interviewing ended when new categories or concepts ceased to appear (Burgess 1982), we would argue that generalisability is best judged in terms of logical inference and the plausibility of the analysis (Mitchell 1983).

Of the 31 who subsequently took part in the study, 17 were female (mean age 29) and 14 were male (mean age 32). Mean forced expiratory volume in one second (FEV1, a measure of lung function) of these adults was 50.7 per cent of the predicted volume for a 'healthy' adult (S.D. 26.3, range 17–115 per cent). Six respondents had undergone organ transplantation, two were on the transplant waiting list (one for repeat transplantation) and one was considering assessment for transplantation. Age at diagnosis ranged from birth to 22 years, although only three respondents had been diagnosed at over five years of age.

The association of socio-economic status in CF health outcomes has not been evaluated systematically (Schechter et al. 2001). Socio-economic status was not measured in these respondents because of the difficulties in assigning a social class category to adults whose choice of occupation and ability to continue working is driven largely by the limitations of CF. At the time of interview half of the sample were not in paid work, mainly due to ill health. Table one shows the social and health characteristics of the respondents. Employment details are not precisely worded in order to protect participants' anonymity.

INSERT TABLE ONE ABOUT HERE

Perceptions of health

When adults with CF talked about their health they often mentioned it in the context of daily activities that their health impinged upon, in much the same way that respondents in Saltonstall's (1993: 8) study spoke of health as 'being in the world'. These references to what might be called health-related quality of life (QoL) were thus difficult to separate out from notions of health. Furthermore, although the majority of adults acknowledged that they had a

chronic illness and referred to the effects of its symptoms, predominantly they spoke of their health rather than their illness and the analysis reflects this emphasis.

Four concepts of health with CF were identified from the data; health as a 'normal' state, health as controllable, health as a distressing state, and health as a release. These four concepts are viewed as cyclical, with movement around the cycle being due to effects of CF, its treatment and the context in which adults were placed. Interviewees did not always refer explicitly to these concepts; rather they were identified as themes recurring throughout the interviews, suggesting that health with CF is a dynamic concept. As each adult spoke about past and perceived future health, as well as their current health, they tended to employ more than one of the four concepts. Adults could be identified as being at (or moving between) certain points on the cycle. The health, treatment effects and contexts that were seen to cause movement between concepts are discussed further in relation to each concept.

In addition, Bury's (1991) distinction between coping and style of managing chronic illness is employed, although in this case in relation to maintaining perceptions of health. Analysing each concept of health in terms of these distinctions resulted in the identification of two styles used by some respondents: fraudulence in maintaining the perception of 'normal' health and denial regarding the concept of 'health as a release'. Three distinct modes of coping were also specified: making comparisons with others, maintaining a positive attitude and acknowledging a loss of spontaneity. Strategies associated with these modes of coping were noted.

The four concepts of health will now be considered in turn, noting the treatment effects and contexts that lead to movement between them, and the use of different styles and modes of

coping. This will be followed by a case study that illustrates the dynamic and cyclical way in which these concepts are used over the lifecourse.

(1) CF as a 'normal' health state

The first concept of health with CF that was identified is CF as a 'normal' health state. One style and one form of coping used by some respondents to maintain the perception of being 'normal' were established. The style of perceiving oneself to be fraudulent about claiming to have CF is explored first, followed by the mode of coping through making comparisons with others without CF.

Adults variously defined 'normality' as not requiring hospitalisation for CF, or being in employment without needing any more sick leave than a 'healthy' person. Normality also included having an active social life, including participating in sports without ill health impinging, in the same manner as has been discussed by respondents without chronic illness (Saltonstall 1993). In his study of adults with diabetes, Kelleher (1988) was able to count the number of respondents who considered their health to be 'normal'. In the present study, it was impossible to count the total number of adults reporting 'normal' health, due to their accounts of changing health through their lifecourse and the ambiguous nature of what 'normality' was for them.

Eliza, aged 31, was married with a two-year-old daughter conceived by IVF. By disregarding the minutiae of ill-health effects of CF, such as coughing and occasional breathlessness, and focusing on the wider picture of her QoL instead, she claimed that overall CF did not impinge on her ability to maintain 'normal' health. This is similar to the category of 'health despite disease' identified by Blaxter (1990) in her Health and Lifestyles survey. Eliza's perspective

of being able to enjoy 'normal' health over a lifecourse with CF encompassed work, relationships, parenthood and social life, i.e. health was seen as the capacity to function 'normally' in all aspects of life. Eliza saw this 'normal' life as applicable not only to herself but also to adults with CF as a group; for example, she noted correctly that within the health care professions there were doctors and nurses who have the disease (Niven 2000):

'They [people with CF] can marry, they can have careers. I mean there's doctors with CF, there's nurses with CF, they can have families, they can have a normal life. I class myself as a normal person...I have rows with my husband, I shout at my daughter, I run a home and I'm very active.'

For most adults, however, the concept of normality was less precise. Cornwell (1984: 145) rightly stresses the importance of understanding the context in which concepts of health (and illness) are used in order to understand their meaning fully. Adults interviewed in the current study found it difficult to describe to their complete satisfaction the meaning of health for them due to the different contexts in which they could perceive their health (e.g. as a patient in hospital, as an employee at work, as a parent of young children). Rose, aged 27, was not diagnosed with CF until she was 15, although she reported being given copious amounts of antibiotics by her general practitioner for chest infections during her childhood. At the time of her interview Rose was married, employed part time as a health care professional and had had two children with no adverse effects to her wellbeing, yet was receiving regular nebulised medication and antibiotics for frequent chest infections. She was therefore unsure whether to conceptualise her health as normal:

'One friend says, "Well, you aren't well" and I think, "Well, but I'm not ill." So if I'm not well, but I'm not ill, what am I?'

Bauman suggests that ambiguity arises from the modern-day notion of it being necessary for a 'norm for every area and aspect of life' (1998: 222) to maintain order in the social world. In the field of health, therefore, a 'norm' might include working and having children (being 'healthy'), yet would not include taking regular medicines to treat chest infections (being 'ill'). Rose's uncertainty over the classification of her health reflects the medical uncertainty currently inherent arising from a very variable disease course. For example, receiving a CF diagnosis after age 18 has been associated in the USA with fewer complications, fewer courses of IV treatment and less use of enzymes (Wideman et al. 2000). The recent increase in late diagnoses of CF is due in part to advances in genetic diagnosis whereby those with milder forms of disease are now identified more easily through genetic testing. Conversely, those adults in this sample who had been diagnosed late often reported their parents' long battle with doctors before a diagnosis of CF was made.

Fraudulence

The style used by adults to maintain their perception of their health as 'normal' was for them to feel that they were a fraud in their (or others) claim that they were a person with CF. Four women and one man (all unprompted by the interviewer) said that at some time in their medical careers they felt like a 'fraud', as they did not fit their own perception of a 'CF patient'. This was someone who coughed a lot, had frequent hospital admissions and a strong family history of the disease. People with CF maintain regular hospital contact throughout their lifetime by attending outpatient appointments for routine treatment and care, so there were many opportunities to observe the health of others with the disease. Two adults reported that they had spent long periods believing that they had been misdiagnosed in childhood, although they had acknowledged that they had had a 'health problem'. As found in a study of

adults with an HIV positive diagnosis (Crossley 1998), adults in the present study were not denying that they had a health ‘problem’: rather, they were uncertain about their health in relation to the medical profession's view of it. In this manner, a style is not only the way people respond to illness features or treatment regimes (Bury 1991) but also how they respond to the medical profession's notions of disease. For Keith, a 26-year-old trained bookkeeper who lived with his partner, it was the appearance of ‘mild symptoms’ in his early twenties that convinced him he was not a fraud. The notion of having CF ‘in the family’ was strong and indicates that respondents were aware of genetic links (Conrad and Gabe 1999, Kerr et al. 1998) concerning CF:

‘But it seems very strange to me that there’s absolutely nobody else in the family with it. I mean certainly when I was younger, because of that, I used to quite often think I’d been misdiagnosed, and that I had something else. I knew I had a health problem, but I quite often thought, "I wonder if I really have got CF because I’m not exhibiting any of the symptoms I’m meant to" because at that time I wasn’t coughing at all. But it seems to have come true! It seems that I have got mild symptoms now.’

Rose, aged 27, was considering having a third child yet was reluctant to contact the CF Trust for information about whether any other woman with CF had had more than two children, and, if so, whether they had experienced severe changes to their health. Unlike others with CF that she had reported seeing or reading about, Rose stated that she had suffered no adverse changes to health during or after her pregnancies and so felt fraudulent about seeking information from the CF Trust on others’ experiences. In this respect Rose's ambiguity over her perception of her health acted as a barrier to getting information about her health and the experiences of others:

'I've been tempted [to contact the CF Trust] but I feel a bit of a fraud because I don't consider myself unwell as such. A lot of problems other people seem to have I don't seem to have.'

These feelings of being fraudulent about being seen or treated by others as someone with CF may arise in at least two ways. First, doctors had reportedly told the parents of many of these respondents that their child would encounter serious illnesses and not live past childhood, and at that time this was the usual outcome for children with the disease. Often it seems that parents had passed this information on to their children once they reached their late teens; indeed many respondents mentioned this during their interviews. Others stated that their parents had celebrated 'milestones' such as special birthdays, adding to the feeling of fraudulence as they lived past their predicted survival age in relatively good health.

The second factor that may be influential in adding to feelings of fraudulence is the ambiguity about what should constitute 'health' for adults with CF. Respondents reported that they felt the lay public, if they were aware of CF at all, still saw it as a 'child-killing disease'. Although advertising by the CF Trust now reflects the increase in survival age by using pictures of adults with CF during fundraising, publicity material during these individuals' childhood traditionally used images of sick or dying children to raise money and awareness. Indeed, the concern of adults with CF over the implications of some organisations continuing to portray CF as a 'child-killing' disease (for example in fundraising) has previously been raised in America (Stockdale 1996). It is of note that many respondents in this study stated that they did not currently maintain close contact with the CF Trust, preferring their parents to continue receiving the charity's newsletters.

Comparing oneself to others without CF

The mode of coping used by respondents to maintain their perception of health with CF as 'normal' was to compare their health to that of others without disease. Comparisons by people who are chronically ill with healthier others have been termed 'upward' comparisons, with these others being seen as 'better off' (Franz et al. 1997). In the study reported here, however, interviewees who considered their health and QoL to be 'normal' tended to describe people without CF (or another chronic illness) as being no more healthy or fit than themselves, so using the 'upward' comparison to enhance their own perceived health status. This use of 'upward' comparison is also in direct contrast to Waddell's (1982) finding that people with CF were encouraged by hospital staff in Australia to make downward comparisons to 'less fortunate' others such as those with spina bifida, a technique he termed 'neutralisation'. Whilst acknowledging that some people with CF were living into their thirties and most had no 'embarrassing symptoms' or 'deformities', Waddell postulated that neutralisation was encouraged by the CF clinic as it 'may not avow their imputed inferiority but does enable the condition to be more palatable to them' (1982: 217).

Keith, the 26-year old trained bookkeeper, stated that he compared himself currently to other people at his workplace who were of the same age. While a few of these people were seen to be 'super-fit' through exercise, most were felt to eat, smoke and drink too much; thus it was the latter who were behaving 'normally' by not paying attention to and caring for their body. In Keith's case his claim to being 'unfit/normal' was thus due to choosing actively not to control his body through exercise, in the same way as his unhealthy colleagues, rather than as a result of having CF:

'There are a couple of guys at work who are really super-fit and they'd go out and run the London marathon tomorrow morning without even thinking about it. And I'd love to be like

that, I'd love to be that fit. I don't do anything about it, so I've probably got no right to want to be like that [laughs]...but the majority of my colleagues at work are a little bit overweight, or smoke too much or drink too much or party far too hard. So you know, I'm certainly not the sick boy of the company or anything like that.'

Oscar, 26, a computer worker, calculatingly used 'normal' healthy people as a measure of physical capacity and performance against which he could build on his improved 'normal' health post transplant, such that he now saw his health as being better than that of healthy people. This notion was similar to Crawford's (1984) suggestion that health is a distinct goal that can be achieved through willpower and self-discipline. In drawing on 'normal' healthy people as a social resource and comparing himself to them he developed a strategy for improving his health. Oscar observed:

'I do compare myself to my friends 'cause I know I can be better than them, so actually I strive to be fitter than them in certain circumstances. So I compare myself to them so I can better them in that way, because that's like a challenge to me and I have actually achieved some of those, as I say I've been going down the gym now since February.'

Keith and Oscar's comparisons illustrate Crawford's (1984) concept of health as self-control: Keith chose to compare himself to those without self-control in contrast to Oscar who compared himself to those with it. This difference may be explained by the fact that Keith was concerned about starting to approach the 'slippery slope' of declining health, brought about by the progression of the disease, whereas Oscar had made a successful recovery from a transplant 18 months previously. Indeed, Oscar's health post transplant is explored further within the concept of health as a release. Crawford (1984) also defined the concept of health as a goal that must be achieved through reliance on health-promoting behaviours such as diet, exercise and not smoking, requiring commitment and energy. Both Keith and Oscar's accounts

make reference to such health promoting behaviour and mirror the concept of health as being one of functional fitness (see, for example, Blaxter 1990, Calnan 1987, Williams 1983).

(2) Health as a controllable state

The second, and most frequently expressed, conceptualisation of health with CF was that it was a controllable state. The use of the term ‘control’ here implies control of everyday life and settings (Bury 1991) through an attitude towards health. This is in opposition to the concept of health as self-control identified by Crawford (1984), and discussed above, which stresses the notion of self-control of the body through physical means. For health as a controllable state to be perceived as being maintained, a greater degree of control in everyday life, the manipulation of social situations and the setting of realistic goals were required (Bury 1991).

Most commonly, the commencement of intravenous (IV) antibiotics (commonly referred to by respondents as ‘IVs’) marked a change from the perception of ‘normal’ health to one of health as a controllable state. As such it represents an empirical example of the ‘biographical disruption’ (Bury 1982) caused by the onset of chronic illness in previously healthy people. Having IVs changed the respondents’ perception of their health because it was clear to them through comparison that most ‘healthy’ people would not routinely have need of this treatment. Having coughs and colds (but not chest infections) up to this point had been seen to be part of ‘normal’ health, because everybody was thought to experience them and they were not usually attributed to CF. Only when the infections required IV treatment for their eradication were they perceived as part of the illness that was CF. This treatment was usually seen as signalling the beginning of a period of declining health and it was then that the interviewees talked of chronic illness as ‘consequence’ (Bury 1991: 453), for example

disrupting home and work life, and perhaps leading to a search for more information about the disease. Respondents often described this decline in health as the beginning of the ‘slippery slope’. Keith, aged 26, referred to his health when younger as ‘normal’, but later in the interview acknowledged that his health would change over the course of the disease:

‘I’m very much of a mindset that once you hit 20 you are on a slippery slope downwards I think...And I suppose yeah, there always has been that slippery slope element.’

The idea of a slippery slope is similar to the notion of ‘going downhill’ or ‘downward trajectories’ (Strauss and Glaser 1975) found in accounts of others with chronic disease (Jonsen et al. 1998). Younger respondents (i.e. teenagers and those in their early twenties) reported anticipating this change to their health state whereas older ones (i.e. those in their late twenties and thirties) looked back on needing IVs as a marker of when their health first started to deteriorate seriously.

Although no style of ‘control’ was identified in the interviews, two modes of coping to maintain control were noted. The first was to view CF as beneficial to overall QoL and to express a positive approach towards it, while acknowledging the part played by luck or fate in the maintenance of health. This was upheld by making favourable comparisons between their personal health and that of others with CF (i.e. making a lateral comparison). The second form of coping was to acknowledge the loss of spontaneity that having CF entailed and to adapt social life and daily activities accordingly. It is to presenting a positive attitude that we now turn.

Maintaining a positive attitude

The majority of adults mentioned maintaining a positive attitude towards CF. Indeed, the lay concept of health as being an attitude of mind, and in particular using psychological approaches to control physical health, has previously been noted in the sociological literature (Calnan 1987). Many spoke of the ways in which they believed CF had made them stronger people, or had given added meaning to their lives because of their positive attitude towards it. For example, Vanessa, an 18-year-old student, when talking about the meaning of CF to herself currently, stated:

'I think it [CF] makes you a stronger person...and also I think I'm more mature at my age ...because I've seen things, I've coped with things, I've had injections and operations and it makes you grow up, so yeah, it has its good sides as well as its bad sides.'

This attitude is in stark contrast to that found by Charmaz (1983) in her study of people with a variety of chronic illnesses, including heart disease, cancer and multiple sclerosis. Charmaz noted:

'The language of suffering these severely debilitated people spoke was a language of loss. They seldom talked of gaining a heightened consciousness of the world, revelations about self or insight into human nature from their experiences.' (1983: 191)

For a few respondents the advent of CF-related diabetes was reportedly also met with a positive response. Although for others the thought of becoming diabetic was distressing (see below), for Eliza, 31, being told by doctors that she now had diabetes was not allowed to dent her positive attitude to CF:

'It's [diabetes] not been a problem. 'Cause when they [doctors] said, "You've got the diabetes" I had all the train journey to get used to it, coming home and I walked through the door.And I'd obviously got used to the idea 'cause I said [to husband], "Well, it'll only be another tablet or two". He [husband] said, "Eliza, you're so cool about it". I said, "Well, there's nothing, if I've got it, I've got it, if I haven't, I haven't."

Respondents in Blaxter's (1983) study of women's perceptions of the causes of disease spoke of illness as a weakness, or of giving in to certain diseases. In contrast, Eliza implies that she is not 'giving in' to CF-related diabetes by maintaining her positive attitude towards it. Interestingly, Eliza was one of a few adults whose account of health could be categorised as both 'controllable' and 'normal' at different points in the interview. This may have been because of ambivalence over the constitution of 'normal' health, or because 'normal' health was treated as a broad concept while 'health as controllable' was used in the context of considering the finer points of the intrusion of CF and its effects. A third reason may be the ability of interviewees to perceive their health as fluctuating between the two concepts on a regular basis depending on the effects of the disease, its treatment and the context in which they found themselves.

Adults with CF also stated that the maintenance of a positive attitude enabled them to influence treatment outcomes, as found in a study of women and cancer (Charles et al. 1998). Similar views have also been reported in other studies of perceptions of health and illness (Cornwell 1984) and illness prevention (Davison et al. 1992). Furthermore, some interviewees reported seeing others 'give up' their positive attitude towards CF and then experience a poorer outcome from treatment than those who were positive about their health. Blaxter (1983) has previously suggested that women are more conscious than men of a link between mind and body, favouring 'mind over matter' maxims for their management of illness. In the

present study, however, both male and female respondents expressed the importance of maintaining a positive mental approach towards their CF.

Although being able to control health by striving to maintain a positive attitude towards the disease was seen as desirable, many also felt that luck, or fate, played a significant part in how much control over health could actually be achieved. As such our respondents were expressing the same views about luck and fate as they had in the context of the risks of organ transplantation (Lowton, in press). In the context of health perceptions, while respondents acknowledged that they were unlucky to have CF, they noted that in comparison with others with CF they were still lucky, as these other CF patients were in worse health than they were, or were unable to carry out the same activities as themselves. Such comparisons were made possible because it was felt to be relatively easy to identify people who had CF and were ill (for example because they had laboured breathing, required supplemental oxygen or were seriously malnourished). For instance, Jack, a 35-year-old civil servant, stated that:

‘If I do see someone who’s really bad, they might be carrying an oxygen bottle. I think well, I’m really, you know, without putting them down or anything, I really think well, yeah, it could be worse. I’m grateful it hasn’t deteriorated to that state, or I’ve never got to that state. So yes, I suppose I do [compare] in that way, yeah.’

Those who saw their health as controllable thus helped maintain a positive attitude by comparing themselves ‘downwards’ against a ‘visible’ other who was more severely ill than themselves. By making this comparison they endorsed the view of their own health as being good, and played down the prospect that they would suffer the same fate as adults with CF in worse health than themselves. In doing this, however, the reality of luck influencing health state was acknowledged.

Acknowledging and minimising the loss of spontaneity

The second mode of coping used to maintain the perception of health as controllable was to acknowledge a loss of spontaneity and, on occasion, note how this was minimised. Interviewees reported that loss of spontaneity resulted from constantly having to think about how their health affected what they could do in their everyday lives. Again, coping lead to the formation of strategies aimed at minimising the loss of spontaneity. Adults had to be more careful than other people, for example by avoiding those with chest infections, and needed to plan more, for example when travelling or contemplating having a family. During their interviews respondents did not necessarily perceive a great difference in the level of QoL achieved compared to others, but stressed the amount of work needed to maintain a good QoL (Strauss et al. 1982). For example, the amount of work and planning that had to be done both before and during travelling, getting the hospital to assess them as ‘fit to fly’ and obtaining doctors’ letters regarding medication, was routinely mentioned.

Most work was achieved ‘backstage’ (Goffman 1963), with control of health occurring out of sight in order to maintain the image of being ‘normal’, although ‘frontstage’ work (e.g. taking regular treatments in view of others) also occurred and is discussed below. Respondents described two features of their management of the image of normality; first, keeping treatment separate from daily life and, secondly, keeping acute symptoms hidden from others.

Nicholas is a 37-year-old adult who held down a full-time office job and prided himself on taking less sick leave than his ‘healthy’ colleagues. He described how he attempted to keep his treatment separate from daily activities by compartmentalising his backstage work, physically trying to ‘bracket off’ or normalise the disease so that its effects on his identity remained relatively slight (Bury 1991). In keeping CF treatment hidden from public view,

respondents could pass as ‘normal’ and so did not have to counter views of others that might question their ‘normality’. As Nicholas explained:

‘I do me stuff [physiotherapy and drug treatment] in the morning, I go and do a normal day like everybody else does, I come home and do me stuff [physiotherapy and drug treatment] in the evening, then I try and have a normal evening like everybody else does.’

A few respondents indicated that they tried to integrate treatment into their social life in an attempt to minimise the felt loss of spontaneity. Treatment appeared to take place ‘frontstage’ only when they were in the company of acquaintances or friends, and where there was a desire not to interrupt the social activity that was taking place. In this manner an individual with chronic illness may control social interaction by making others come to terms with the reality of their health problem while not letting that reality take over (Strauss and Glaser 1975). Indeed, Anna, aged 31, reported that she did not allow CF to dominate when choosing to take her 11 enzyme capsules in public, in contrast to most other adults who took them in private, or ‘backstage’.

Keeping acute symptoms hidden from others was also part of the attempt to create an image of normality. Symptoms like pain, unlike most treatments, were difficult to manage because of their unpredictability and had to be dealt with as and when they arose, thereby affecting spontaneity. For Anna, ‘backstage’ was the place to manage the pain she occasionally felt from her liver transplant scar because she felt no member of the audience would intrude. As she explained:

'You're in so much pain you don't want to move but I just want to be left on my own, you know, 'cause I don't want anybody to see, I just want to get back on my own and then get back out and do all the normal things'.

Backstage/frontstage work, however, and acknowledging a loss of spontaneity, did not continue indefinitely. Eventually maintaining the perception of health as 'normal' or 'controllable' failed, and health with CF became 'distressing'. It is to this notion that we now turn.

(3) Health as a distressing state

For some, health was seen more as a distressing state. For four of the sample it was a constant, all-encompassing aspect of their current wellbeing, although they continued to refer to their health rather than their illness during their interview. For three other adults, the distress was specific to certain aspects of CF. No new styles, ways of coping, or related strategies were identified in relation to this concept; rather, the emphasis was on an inability to maintain successfully a previous mode of adaptation. Thus a means of coping or strategy might have been rejected as inappropriate because it had not worked, despite an individual's best efforts, while a style might have been abandoned because it had not been applied positively, for example by comparing oneself unfavourably to others, as opposed to favourably. We will consider both versions of 'health as distressing' in turn, beginning with it as 'all-encompassing'.

Wendy, 23, and not currently in paid work, defined a 'normal' life very much like Eliza had done previously, in terms of having a job, being married and participating in leisure activities. However, although younger and arguably in the same health (both were diabetic and both had had IV antibiotics at home), Wendy reported that she felt a 'normal' lifestyle, similar to that

of those without CF, would not be achievable for herself. This was in stark contrast to the feelings of fraudulence that she said she had felt two years previously when her father had stated that he had not expected her to live into her twenties. For Wendy, normality was defined by activity, 'doing normal things'. Coping by comparing oneself to a healthy person could be found in her account, although she viewed the comparison negatively instead of positively. As she put it:

'...just a simple journey has so many hurdles that you just sit there and think, "A normal person wouldn't have this". My friends are moving on and achieving things, getting careers and having this and that, and mine's becoming more and more restricted and you just try and avoid facing up to it so you're not doing the things you can't achieve...I'm not going to be a normal person who could just go and do normal things.'

From this standpoint, then, 'health as distressing' involves daily disruption to work, social relations and hopes for the future as a result of the effects of emerging chronic illness. In this context it is important to note that although those in the current study have been chronically ill since birth, the disruption to their biographies did not begin for most of them until they had lived for perhaps 20 years with the disease.

Another who saw 'health as distressing' as all encompassing was Clare, a 35-year-old recently married university professional. For her the notion of being 'normal' was part of the identity of a person, as opposed to their functional ability. Clare attributed the perception of her self-identity as 'abnormal' to the attitudes of doctors during her treatment as a child and stated that she was now having psychotherapy to come to terms with her CF. In this case chronic illness represented an attack on the individual's sense of identity and self-worth as much as their physical self, such that a loss of confidence in the body led to a loss of confidence in social

interaction (Charmaz 1983, 1991). Contrary to favourable comparisons made by adults who saw their health as normal or controllable, Clare's comparison to others put her identity and self-worth in an unfavourable light:

'I did [make comparisons] as a child, I think. That was quite a strong thing, especially when they [doctors] used to use words like "normal". Normal people and me. So that, I think that remains in you'.

The influence of older age, or coming to the bottom of the slippery slope, was a significant factor in perceiving health as an all-encompassing, distressing state, and often came about because the disease had progressed so far that it was no longer possible to maintain or control health by any of the previously discussed strategies. Graham, aged 40, is an ex-hospital ancillary worker living with his wife and stepson. He stated that now he could not walk more than 100 yards because of his poor lung function. Graham reported that he liked to compare his lung function results with other men at the hospital outpatients' clinics, but was always distressed that his readings were now lower than others'; at the time of his interview Graham's FEV1 was only 22 per cent of that predicted for a healthy adult of his age and height. As Bury (1991) notes, comparisons with others may be a source of worry if the resulting contrasts prove unfavourable. Graham also reported constantly attempting (but failing) to keep up with 'healthy' people by trying to walk at the same pace as other men of his age, or by unsuccessfully attempting household chores in an effort to maintain his perception of being able to control his health. Indeed, maintaining the self as organised requires empirical validation in daily life (Charmaz 1983), and this is what Graham was attempting, albeit unsuccessfully.

Chronically-ill people may view their developing limitations and their loss of control as ‘losses of self’; losing their former identities without developing new, equally respected ones (Charmaz 1983). Indeed, Graham reported remembering himself as being ‘healthy’ in the past, in his roles as a hospital ancillary worker, a husband and a stepfather. However, he did not perceive himself to be ‘normal’ any more in terms of identity, physical functioning or social activity, despite trying to be:

‘I do try so hard to live a great big lie, that I’m alright [‘normal’] really. It hurts. The last couple of years, where I’ve had to, I got made retired from my job and all these things, all of a sudden you get to 38, 40, and it’s become, it’s an achievement to me, but I try to be normal, but I get kicked down every time’.

As Blaxter (1976) notes, not only does an individual's definition of health currently depend on his or her memory of health in the past, but also the meaning of that past depends upon what has happened subsequently. Graham's health was perhaps distressing to him now because his frequent memories of ‘then’ were of a ‘normal’ health and QoL.

Another three adults reported that their health was currently distressing only in regard to certain aspects of the illness; namely the risk of infection, the potential onset of CF-related diabetes and waiting for a suitable donor organ to become available for transplantation. Matthew, 32, was a married ex-craftsman who stated that he was distressed about threats to his health from infection (in particular *B. cepacia*) and tended to monitor his health much more closely than did others with CF. He noted:

‘To all intents and purposes I monitor my health far more than the average person. I’m under the [hospital] and scrutinised a lot’.

As with others who were distressed about their health, Matthew tended to compare himself to those with CF who appeared in better health than he was (as opposed to those who saw their health as controllable and referred to others whom they perceived to be in worse health). Like Clare, Matthew referred to anyone without CF as ‘a normal person’ and was waiting eagerly for gene replacement therapy (GRT) trials to improve his health by keeping as well as possible, primarily by avoiding infection.

Another cause of distress to adults was the possible onset of CF-related diabetes, recently estimated by doctors to develop in 13 per cent of adults at one specialist centre (Yung et al. 1999). Nicholas, the 37-year-old office worker, reported diabetes as being something that he would not be able to cope with because his current capacity to control his health successfully would then be jeopardised. Unlike Eliza, referred to earlier, he talked of the distress caused when doctors at the hospital thought that he might have CF-related diabetes, and performed some preliminary tests before recalling him to the hospital for further investigation, which he attended with his wife. Again reference is made to ‘going downhill’:

‘And I have to say, I mean anything like that [diabetes], which is a definite downer, I mean it cracks me up... it was only a few days after that [first test] we went back for some more tests and it proved that it was all okay. And the relief of that is just phenomenal. I don’t want to go downhill, and to know that I’ve then got to start taking more medicine. I don’t think the tablets would have worried me, about having diabetes, but the fact of having something else wrong on top of it [CF], something else to control, maybe having to start injecting. I think I put up with enough as it is, and I don’t want any more. What my threshold is, I don’t know, but I don’t want any more. And to be told, I mean as soon as I found out I told me wife and there’s both, she was crying one end of the phone, I’m crying, this was when we first thought I might have it.’

In contrast to the concept of health as controllable, health as distressing involved luck or good fortune coming to an end and 'bad luck' beginning to surface. The latter is similar to Blaxter's (1983) finding that lay people report the randomness and inevitability of disease to be threatening.

Periods of distress were also identified when adults spoke of being on the waiting list for organ transplantation and having to carry a hospital pager to alert them when donor lungs became available. The pager added to an already poor QoL that was caused by rapidly failing health. This period was distressing not only because there was a chance that no matching donor organs would be found in time to prevent death but also because adults needed to stay near the hospital or remain in close contact with hospital staff. Additionally, physical and emotional work had to be performed by adults in order to remain well enough for surgery (Lowton, in press). Furthermore, those who had had a transplant reported the distress of false alarms when someone telephoned the pager accidentally, or when it went off because the batteries were low.

Sadly, there are currently just two possible outcomes after health as distressing is experienced as an all-encompassing state. The first is death, most commonly due to respiratory failure (Madden 2000). The second is recovery from a successful organ transplant. The last concept identified is best characterised as 'health as a release', and was employed after such a transplant. It is to this concept that we now turn.

(4) Health as a release

Discussion of health as a release is brief for two reasons. Firstly, only six respondents who had successfully recovered from their organ transplant had experienced the ‘release’ of post-transplant life. One style was identified within this concept: denial of CF. No ways of coping or related strategies were identified, most likely because interviewees reported feeling so well that none were required to maintain their perception of good health. Secondly, other adults, looking forward to a time post-transplant, noted some of the positive effects of this procedure (for example, taking less medication and ceasing to experience breathlessness and chest infections). Perceptions of transplantation, however, could not be conceptualised as a release for those who had not had a transplant as this concept encapsulates more than just one or two benefits of surgery. The term ‘release’ is used here, following Crawford (1984), in contrast to the disciplinary regime for health (i.e. self-control). As Crawford (1984: 81) notes, ‘release is the antithesis of discipline, disengagement or extrication from imposed and internal controls’. Release for adults post-transplant in the current study was noted as being both physical and emotional.

Health as a release was such a strong feeling that respondents could easily distinguish between health pre and post transplant. When asked directly about what her QoL meant to her, Harriet, aged 34, an ex-council worker who had had her heart-lung transplant 10 years previously, noted the difference that her operation had made to her:

‘I suppose I can actually differentiate between the two, having a poor health and then having good health.’

Barry, a 39-year-old trained bookkeeper, had had his heart-lung transplant 18 months prior to the interview and could quantify the vast physical improvement to his health post transplant.

He recalled being able to swim just two lengths of the pool in the period immediately preceding his admission to hospital for surgery, compared to 30 lengths soon after discharge:

'I'd do a length and end up coughing my guts out before I could do the other one, and I kept going but it was very difficult. I mean now I can regularly, I'm just building up speed and stuff and I do thirty lengths when I go to the pool, which is 1000 metres.'

Respondents who had had a successful organ transplant also spoke about regaining spontaneity, mostly due to not having to spend so much time on treatments. Harriet referred to the spontaneity she had enjoyed post transplant and how this had continued up to the present day:

'To me it [health] just means I can do everything without thinking about it. Um, not have to go out prepared. You know, if I fancy just going to the shops I just put me coat on and go, where before I had to do meself up for it. Have me nebulisers, take your antibiotics, be in the right frame [of mind] really and then go for it. It's so different.'

Here health was an emotional as well as physical release; Harriet reported not having to be mentally prepared or in the 'right frame of mind'. The previously identified means of coping by acknowledging a loss of spontaneity could be abandoned, adding to the sense of release. For those adults who had had a transplant there was initially a tremendous change in their health, returning the individual to a state of near 'normality' once returned from hospital.

Although transplant recipients with CF have to exchange a daily antibiotic drug regime for a daily immunosuppressive regime (Madden et al. 1992), respondents in this study felt that their current medication was far less restrictive than the distress that their CF and past treatment had caused, as Oscar explained:

Author: You talked about restrictions. What restrictions [do you now experience after transplantation]?

Oscar: Very, very little ones, I wouldn't like to call them restrictions, I have to take tablets regularly morning and evening, I'm not allowed to miss them, 'cause they're me anti-rejection drugs. There's, if I was going away, I'd have to make sure that I had proper medication, I'm restricted to going abroad to certain places,

Author: Is that because of getting drugs out there?

Oscar: No, it's because I'm immunosuppressed so there's parts of the world where they [hospital clinic] don't advise you to go. Really, actually, I'm not that restricted at all now, I lead a normal life, so just being more careful than anything else. I tell you one restriction actually which is a bit silly, I'm not allowed to eat certain types of food, like seafood, soft cheeses, things like that, because they're a possible risk for infection. Now a couple of things that I would love to eat, I mean the other day I was down the pub, and I do love seafood, and we were given a load of seafood, cockles, muscles and that, and I was in absolute purgatory because everyone was eating and enjoying them and I couldn't touch them. I don't really class that as restrictions, and affecting quality of life, I mean compared to what I was before, that's nothing. I mean there's just little things that, um so no, actually, I take that back, I don't really think I have really any restrictions nowadays.

In this sense transplantation can be seen as a transformative experience that radically alters an individual's sense of self, with transplant recipients talking about having been 'reborn' or having a 'new lease on life' (Sharp 1995: 372).

Denial of CF

Denial of disease was identified as a style for three adults who saw health as a release: these were individuals with CF who claimed that their current health problems were not due to the disease. Despite being a genetic disease not 'curable' by surgery, two women, Harriet and Lauren, stated that they did not have CF any more following their lung transplants. This was the only time that respondents were completely at odds with the view of medical science that

transplantation could not ‘cure’ CF. Indeed Harriet, 34, stated that she had become frustrated with her doctors’ apparent failure to take account of the ‘fact’ that she had been ‘cured’ as a result of her transplant:

‘They [doctors] talk to you as if you’re still suffering with cystic fibrosis, and you feel like saying to them, apart from [consultant] ‘cause if you see her she knows straight away, but you think you should say to them “Look, do you know that I’m not ill any more? Have you read my notes?” They talk to you as if you’re still suffering with it.’

Goldbeck (1997) notes that denial, as a defence mechanism, is an abstract and complex psychological concept seen commonly in cancer and heart disease patients. However, rather than being viewed as a negative attribute (Goldbeck 1997), denial may have an important adaptive value (Doehrman 1977). Lauren, a 22 year old ex nursery worker who had become paraplegic after her lung transplant surgery, stated that she could do anything others (with or without CF) could do because she no longer had the disease, although she herself acknowledged that this perception was ‘weird’:

‘It’s weird, because I don’t class myself as CF. Like I say to people, um, before my transplant I had CF, and now it’s like I say to them, “Oh, well, I had CF, it’s like, but I haven’t got it now”. It’s funny, it’s just weird.’

Denial of the identity of an adult with CF can thus be seen as one form of health as a release. Such denial has not been reported before in these adults with CF. This may be in part due to the methodological difficulties in studying this group of adults. As Garay-Sevilla et al. (1999) note in the context of denial of disease in adults with diabetes, recruiting adults from a hospital department or self-help group is not the best way to identify potential deniers. Lazarus (1983) suggests that the maintenance of mental health requires a degree of self-

deception, and that there is a difference whether it is the fact that is denied (in this case having CF) or the implications (acknowledging the organ donor as a person, or possible rejection of the transplanted organ). In this case, denial of CF can be seen as another aspect of positive thinking, using a psychological approach to influence psychological health (Crawford 1984).

To summarise, four concepts of health have been identified from CF patients' transcripts; health as normal, controllable, distressing and a release. Which of these concepts is referred to in turn seems to depend on the effects of CF and its treatment and a changing social context, indicating the dynamic nature of health. The next, final section briefly offers a case study that illustrates the cyclical nature of the concept and its dynamism as expressed by adults with CF.

Health with CF- a life-course approach

The notion that concepts of health in CF are referred to in a cyclical fashion, from 'normal' through controllable, to distressing and on to release, can be seen in Oscar's account of his health from early teenage years up to the time of his interview. Analysis of the transcript revealed that Oscar, 26, who had had a heart-lung transplant 18 months prior to the interview, considered that his first period of 'normality' had lasted until his twenties, when his treatment was minimal and chest infections few:

'I mean right up until I was 19, 20, I really led a pretty normal life'.

Indeed, it has been shown in this paper that adults generally perceived themselves as 'normal' until they required regular IV antibiotics in an attempt to control health, and this was the case with Oscar. However, Oscar reported that his health had deteriorated so severely by his early twenties that it became distressing: he needed overnight oxygen, could not walk further than 10 yards at a time and was subsequently put on the transplant list:

‘Really from about 19, 20 onwards I think I started going downhill. Obviously I had it severely enough for them [doctors] to warrant a transplant. So I’d imagine there was, I think I’d probably [have had] about, three or four years left. Possibly five years if I hadn’t have had the transplant; I think I would have died within four years, whatever. So I think it was pretty severe then.’

Following a successful heart-lung transplant Oscar had experienced his health as a ‘release’. He spoke about his release from antibiotics and nebuliser treatments in the same manner as Harriet had, but also spoke of release from restrictions in his social and work life:

‘So the ability to actually do things. Not having to worry [that] I can’t go to certain places ‘cause it’s a smoky atmosphere, things like that. And also the ability to go and earn a living for myself, as opposed to not being able to, you know.’

At the time of his interview Oscar appeared to be leading a ‘normal’ life once again. He reported holding down a full-time job as a computer worker, doing voluntary work one evening a week and taking part in an evening college course. He hoped to be admitted to university the following year and looked forward to leaving his parental home. Subsequently it was learnt that Oscar had got a place at university and was enjoying his time away from home.

The idea that health is a dynamic concept that changes over the life-course is an attractive one and contrasts with terms such as ‘lifespan’ which imply a more static view of ageing (Bury 2000). In discussing a lifecourse approach, not only are changes and stability in social context highlighted (Hockey and James 1993) but also adjustments to perceived health. The suggestion that concepts of health change over the lifecourse has been mentioned previously (Blaxter 1990) although in that instance survey data were used to support the claim. Oscar's

account of his changing health with CF certainly illustrates the need for a lifecourse approach to perceptions of health. Once this is achieved the variable and context-dependent nature of adults' perceptions of the risks of their treatment can start to be understood.

Discussion

This paper has explored concepts of health in adults living with CF, traditionally conceptualised as a fatal childhood illness. Examining these concepts amongst adults who have been chronically ill since birth represents a novel approach to investigating lay perceptions of health and illness. Four concepts of health were identified: health as 'normal'; health as a controllable state; health as distressing; and health as a release. These concepts can be viewed as cyclical, with movement around the cycle being influenced by stage of disease, form of treatment and social context. Thus the commencement of IV antibiotics is seen as the beginning of the slippery slope and a move from health as normal to health as controllable. Similarly, successful organ transplantation can be seen as a 'release' from the restrictions on health and social life that CF had imposed. Two styles for maintaining these health perceptions were identified from adults' accounts. These were fraudulence in claims to be seen as an adult with CF and denial of the disease or its effects. Three specific modes of coping and associated strategies were also identified. These were comparisons with others, seen either as healthy or with CF; maintenance of a positive attitude; and acknowledging and minimising loss of spontaneity.

Insert figure one about here

The four concepts of health are illustrated as a cycle in Figure One above. Arrows indicate movement between concepts and factors influencing this movement.

As the cycle illustrates, death is not mentioned but would be an obvious alternative pathway from health as a distressing state. Indeed, much of the uncertainty and variability found in CF patients' perceptions of health arises from the fact that 'there is still no evidence of a particular age being a crisis point at which mortality rises sharply' (Dodge et al. 1997: 496). Adults can die at any time, for example following sudden acute illness in previously healthy adults; conversely other adults may survive for an unexpectedly long time, as illustrated by our respondents who reported being told by their parents that they were not expected to survive childhood.

These concepts of health bring together the three traditional approaches to examining lay accounts of health and illness. The literature on how healthy people perceive health resonates with our respondents' ideas about health as functional capacity, self-control, release and 'being in the world' while that on the perceived causes of health and illness relates to our interviewees' references to fatalism and the importance of a positive attitude of mind. The third approach which focuses on how chronically-ill people live with their illness proved to be particularly useful as it highlighted the significance of coping, style and strategy. According to Bury (1991), adaptive processes change over time, in response to shifts in interaction with others and changes in the context of illness. In the present study modes of coping were not altered when health became distressing, and were abandoned altogether when health became a release.

Bury (1991) also argues that the use of terms such as 'coping', 'style' and 'strategy' in managing chronic illness must be distinguished more clearly for analytic purposes, although he concedes that this may be difficult to establish empirically. As noted in the introduction, it is well known that the concepts of 'health' and 'illness' mean different things to different

people and it may be here that difficulties in distinguishing between coping, style and strategy lie. However, there was enough similarity amongst people with CF's accounts to enable these to be recognised.

Two styles were also identified that have not been reported before. Some respondents used the style of fraudulence to maintain a perception of health as normal; this seemed to relate in part to having passed the predicted survival age given to respondents' parents. This perception also relates to the current ambiguity of what constitutes health in adults with CF. A commonly-held view amongst lay people is that CF is a 'child killing disease'. Yet, paradoxically, genetic testing has identified many previously undiagnosed adults who appear to have a much milder form of the disease (Wideman et al. 2000). Similarly, the style of denial of CF in adults post transplant is also a new concept. In our study, interviewees used denial in the context of seeing health as a release and may well have an important adaptive value (Doehrman 1977).

Adults with CF are a very medicalised group, used to regular, on-going hospital treatment and care (Madden 2000). This has implications for the findings reported here, as those patients with a positive attitude may reflect closely the views of doctors at a specialist CF centre. Differences in health perception among respondents can be explained by the complex interaction of factors such as the range of perceptions of health amongst the lay public, including between families, differences in health state and styles of managing the effects of the disease.

Overall, this paper has tried to take the exploration of lay perceptions of health forward by seeing health as dynamic and cyclical. Movement between different concepts of health is seen

as the consequence of the stage of disease, treatments provided and the context in which adults are placed. The analysis is of course based on one-off interviews involving retrospective accounts of the lives of people with CF. In order to test the ideas presented here, future research on lay perceptions of health needs to concentrate on studying these perceptions over time, rather than relying on 'snap shot' accounts.

Table one: Social and health characteristics of respondents at time of interview¹

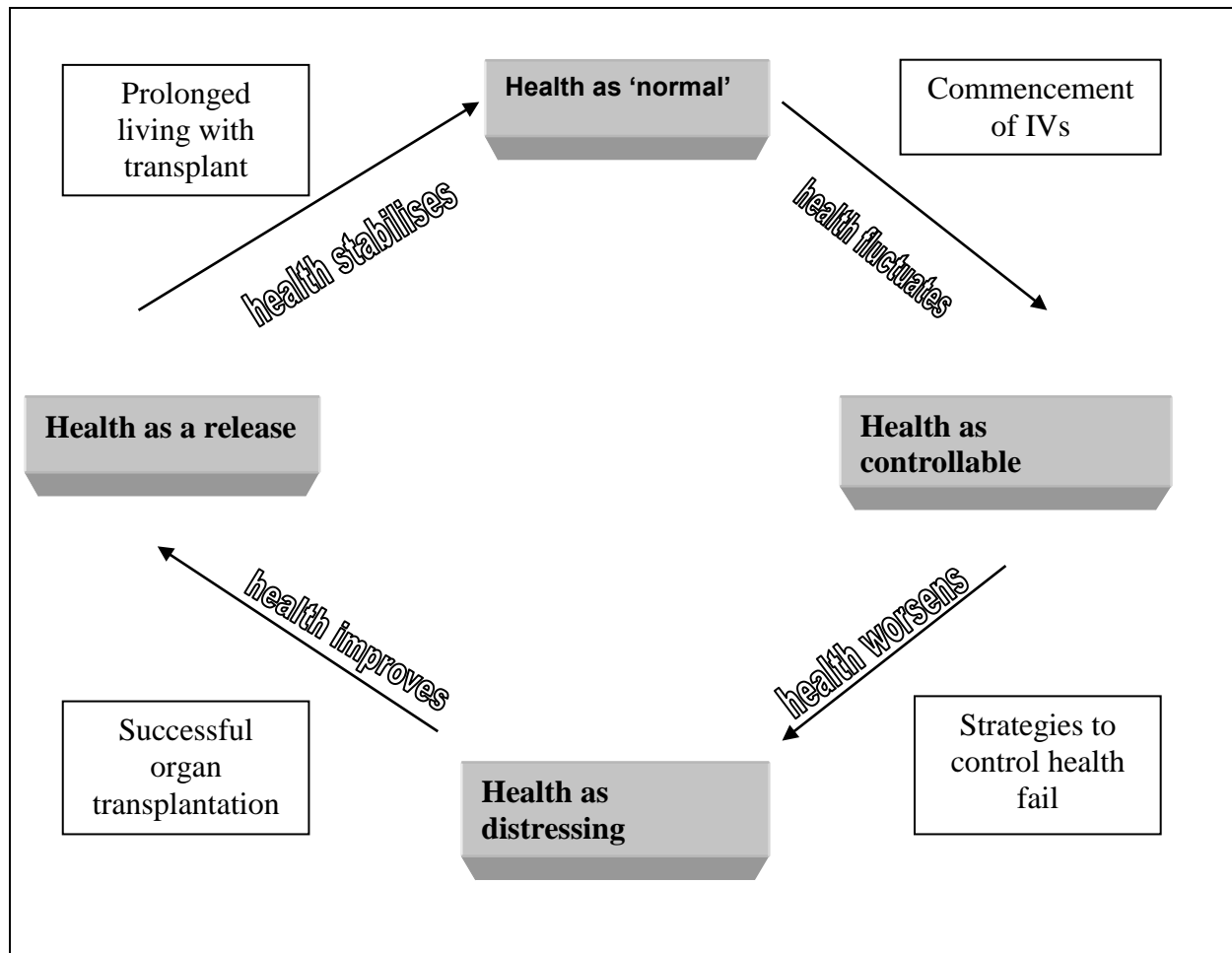
Respondent	Gender	Age	Marital status	Occupation	Diagnosed	Transplant	Children	FEV₁ % predicted
Vanessa	Female	18	Single	Student	At birth	None	No	102
Tessa	Female	21	Single	Student	8 months	None	No	57
Lauren	Female	22	Single	Ex nursery worker	Infancy	Lung, 3 years ago	No	22
Caroline	Female	22	Single	Special needs worker	5 years	None	No	37
Wendy	Female	23	Living with partner	Ex hairdressing assistant	10 weeks	None	No	58
Zara	Female	25	Single	Part-time personnel officer	18 months	None	No	29
Tina	Female	26	Married	Part-time charity worker	10 months	Lung, 2 years ago, on list again for 4 months	No	17
Rose	Female	27	Married	Part-time health care worker	15 years	None	Two	91
Ashleigh	Female	30	Married	Ex shop assistant	2 years	None	Two (one stillborn)	29
Gill	Female	30	Married	Ex receptionist	3 months	None	No	30
Eliza	Female	31	Married	Ex secretary	3 days	None	One	34
Anna	Female	31	Married	Ex shop assistant	2 years	Liver, 9 years ago	One	80
Emma	Female	33	Living with partner	Writer	2 years	None	No	36
Harriet	Female	34	Married	Ex council worker	6 months	Heart-lung, 10 years ago	No	62
Clare	Female	35	Married	University professional	At birth	None	No	78
Nicola	Female	38	Married	University professional	4 years	None	One	58

Catherine	Female	40	Living with partner	Trained legal worker	In infancy	None	No	35
Victor	Male	20	Single	Part-time veterinary assistant	In infancy	None	No	46
Darren	Male	21	Single	Student	At birth	On list for 18 months	No	26
Keith	Male	26	Living with partner	Trained book keeper	5 years	None	No	33
Oscar	Male	26	Single	Computer worker	4 years	Heart-lung, 18 months ago	No	87
Matthew	Male	32	Married	Ex craftsman	In infancy	None	Failed IVF	42
Brian	Male	32	Single	Never worked	In infancy	None	No	23
Charles	Male	33	Single	Ex ship worker	7 years	None	No	26
Mike	Male	33	Married	Engineer	18 months	None	Failed IVF	52
Jack	Male	35	Married	Civil servant	At birth	None	IVF ongoing	68
Ian	Male	36	Married	Ex engineer	22 years	None	Two	57
Nicholas	Male	37	Married	Office worker	3 months	None	No	83
Mark	Male	38	Married	Part-time shop assistant, part-time management consultant	3 months	None	No	35
Barry	Male	39	Married	Trained book keeper	In infancy	Heart-lung, 18 months ago	No	115
Graham	Male	40	Married	Ex hospital ancillary worker	2 years	Considering assessment	No	22

¹ Precise employment details are not given in order to protect participants' identities.

Figure one

The cycle of concepts of health amongst those with cystic fibrosis¹



¹ Sudden and severe illness leading to death can, of course, occur at any point in the cycle.

Acknowledgements

The authors wish to thank all the respondents for their help in this research and Fran Duncan-Skingle, Margaret Hodson and Caroline Shuldham for their advice and support. They should also like to thank Mike Bury and three anonymous referees for their comments on a previous draft of this paper. The study was funded by the Economic and Social Research Council (ESRC) and Royal Brompton and Harefield NHS Trust under the ESRC collaborative case award scheme (award number S00429637060).

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